Pain and its consequences in dementia: Observing the complex relationship between pain, behaviour and ADL in nursing home residents

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CHAPTER 6

Pain assessment in impaired cognition: observer agreement in a long-term care setting in patients with dementia

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Abstract

Aim
To study the application of the meta-tool Pain Assessment in impaired Cognition (PAIC) in a clini cal setting in patients with moderate to severe dementia.

Materials & methods
Observational study in five Dutch nursing homes, where residents were observed by nurses or nurse-assistants during rest and movement.
Prevalence and observer agreement of individual items were examined.

Results
An observer agreement of ≥70% was found for most items of the body movement domain and vocalization domain, although prevalence of these behaviours was low (especially during rest). Items of the facial expression domain had a percentage agreement <70%, especially during movement, but with high prevalence of behaviours.

Conclusion
The pain assessment in impaired cognition items show promising interobserver and intraobserver agreement in a clinical setting.

Keywords:
dementia, interobserver agreement, intraobserver agreement, nursing home, observational measurement instrument, pain, pain assessment, reliability

Practice points
- Since the identification of pain in dementia is essential to prevent negative consequences on quality of life, the use of reliable and valid measurement instruments is very important.
- Pain Assessment in Impaired Cognition (PAIC) research version is a 'meta-tool', consisting of items from existing observational scales for pain assessment in patients with dementia.
- Prevalence and observer agreement for individual behaviours is unclear for the clinical setting with nursing home residents with moderate to severe dementia.
- Prevalence of the individual items varied. Most items with high prevalence belonged to the facial expression domain during movement, lower prevalence was mainly found for the body movement domain and vocalization domain during rest.
- The Pain Assessment in Impaired Cognition items show promising interobserver and intraobserver agreement in a clinical setting, with observer agreement of ≥70% for most items.

Introduction

Pain in persons with dementia is a serious problem. Not only is it thought to be highly prevalent, but pain also has an important impact on the quality of life. Pain may result in challenging behaviour (e.g., agitation, aggression and depression) and may also cause deterioration of physical functioning[1-3].

Besides the altered perception of pain due to neuropathological changes in dementia[4], diminished cognitive and communicative abilities make it difficult to identify and monitor pain in persons with dementia. The ability to self-report pain is seriously challenged with the progressive nature of dementia and is probably a main reason for the poor pain management reported in hospitals, community and home care[1 5].

Therefore, it is recommended to use reliable and valid observational measurement instruments to identify and measure pain in dementia. Several instruments have been developed that utilize observation of pain-related behaviours, vocalizations and facial expressions. Despite the robust development, these measurement instruments often lack sufficient evidence of psychometric properties (e.g., reliability, face and construct validity, responsiveness and usability) and are not internationally implemented [6]. The European COST initiative 'Pain in impaired cognition, especially dementia', put together items for a new universal meta-tool to measure pain in dementia, in other words, Pain Assessment in Impaired Cognition (PAIC), for use in research and clinical settings [7].

The PAIC was based on the best items in available and acknowledged observational measurement instruments, for example, Pain Assessment in Advanced Dementia (PAINAD)[8], Pain Assessment Checklist for Seniors with Severe Dementia (PACSLAC-D)[9] and Mobilization-Observation-Behaviour-Intensity-Dementia (MOBID-2)[10]. Item selection for the PAIC resulted from scrutiny of the evidence, expert opinion from experimental and clinical researchers and multidisciplinary clinicians and alignment with the American geriatric society criteria[11]. The first version of the PAIC consists of 36 items in three American geriatric society domains: facial expressions, body movements and vocalizations. The facial expression domain comprises 15 items, the body movement domain 10 items and the vocalization domain comprises 11 items (Appendix 1, Chapter 5).

Several items included in the PAIC were assumed by the expert panel to be potentially less reliable or valid than others and more viable for bias. However, to avoid making *a priori* assumptions about the utility of these items in the final PAIC, it was decided to allow further empirical item reduction during the validity and reliability testing.

A reliable and valid measurement instrument is important because, in clinical practice, it often affects decision-making for the individual patient. Therefore, the PAIC was developed to identify and monitor pain, as well as to evaluate the treatment of pain[7]. The PAIC-36 has shown good content validity, especially for the body movement domain[12]. In general, items of all three domains were found to be valid in the measurement of pain in persons with dementia[13 14]. The present study investigated the observer agreement of the Dutch version of the PAIC. Observer agreement is part of the psychometric property 'reliability', which refers to the consistency of a measurement[15].

The aim of this study was to assess two aspects of the observer agreement on all 36 individual items of the Dutch version of the PAIC in a real-life nursing home setting: interobserver agreement (different observers evaluating the same situation) and intra-

observer agreement (same observers evaluating the same situation the next day).

By using real-life observations in a clinical setting, the various behaviours and expressions as presented by persons with dementia within the context of an everyday situation could be taken into account. Therefore, it was expected that the observers could observe almost all items of the PAIC. The observer agreement of the individual items was tested in two different situations: during rest and during movement. By doing so, we could also study whether the prevalence of items was different between these situations. Furthermore, by observing the resident during movement (e.g., making a transfer from bed to chair) it was expected that most items of the PAIC would be more prevalent compared with observations during rest alone, due to pain provocation (often) caused by inducing passive or active movements.

Materials & methods

Pain Assessment in Impaired Cognition

The development of the PAIC-36 (research version) is described elsewhere[7]. The Dutch version of the PAIC-36 (Appendix 2, Chapter 5) was translated following the forward–backward approach of the Guidelines for Establishing Cultural Equivalence of Instruments[12][16]. Each item is rated on a four-point Likert scale indicating the degree of presence of the item, in other words, 0) not at all; 1) slight degree; 2) moderate degree; and 3) great degree.

Setting & study population

Nursing homes within the University nursing home network South Holland (UNC-ZH), The Netherlands[17], were invited to participate in this observational study. In total, five nursing homes were included. Residents from different psychogeriatric wards were selected by the nursing staff and, after receiving an information letter, were asked to participate through their legal representative. Residents with a (clinical) diagnosis of mild to severe dementia (Reisberg global deterioration scale (GDS)-score 5–6–7) were included in the study[18]. The presence of (suspected) pain was not an inclusion or exclusion criterion. Given the high prevalence of pain in persons with dementia, it was expected that residents with and without pain would be included and that all relevant items of the PAIC could be observed. Exclusion criteria were residents with Parkinson's disease, Huntington's disease, Korsakov's syndrome, and chronic psychiatric diagnoses other than dementia-associated diagnoses. In these latter diseases, the observation of pain is more difficult and a significant number of items may not occur in these diseases. Also excluded were residents in a vegetative state or coma, as well as stroke patients with facial paralysis which hampers observation.

Observers

Registered nurses or nurse assistants with a minimum age of 18 years and at least 3 months experience as a care professional for persons with dementia performed the observations.

Procedure

During a session of ±30 min, by means of a training video, the nurses were instructed on how to fill out and practice with the PAIC. The training sessions were short because the PAIC is intended to be a measurement instrument which can reliably be used without extended training. Also, for that reason, no specific information was given about the individual items. Observer agreement of the individual items was tested during rest and movement. For example, an observation during rest could be sitting in a chair; however, it was important that the resident was not asleep or drinking/eating. An observation during movement could include a transfer or repositioning in bed (with or without help) as part of care as usual. Each resident was observed for 5–10 minutes by four different observers (Appendix 1 Scheme of observations):

- Day 1: to establish interobserver agreement the resident was independently observed by two nurses at the same time during a resting situation.

- Day 2: to establish intraobserver agreement the resident that was observed on day 1 was again observed by one of the nurses from day 1.

This same procedure was repeated on days 3 and 4 with the same resident, only this time with different observers and during movement. Different observers were used on days 3 and 4 than used on days 1 and 2 to avoid knowledge about patients' behaviours during rest previously which could influence the ratings during movement.

During the observations on day 1 and 3, one member of the research group was present to supervise the start of the observations and to address any questions. The researcher did not interfere with the rating of the PAIC.

The Medical Ethics Committee of the Leiden University Medical Centre approved this study and gave a waiver of consent. Due to the cognitive impairment of the included residents, written informed consent was obtained from the patients' legal representative. When possible, written informed consent was also obtained from the residents themselves.

Statistical analysis

Descriptive statistics were used to describe the demographic and clinical characteristics of the residents and participating nurses. Data are expressed as percentages or means with standard deviations (SDs).

First, the presence of the individual PAIC items was examined, expressed in percentages, during rest and movement. To analyze the percentage presence, in other words, prevalence of the individual items, the scores of day 1 (first observations during rest) and day 3 (first observation during movement) were dichotomized in 0 ('Not present at all') and 1 ('Present in any degree'). Missing scores were recoded into zero, in other words, not present. The prevalence of the individual items was assessed and compared between rest and

movement. Differences were analyzed using McNemar's test for dichotomous variables. The interobserver and intraobserver agreement of the individual items was assessed by examining the percentage agreement. Agreement parameters indicate how often observers who rated the same item during the same situation chose the same response category, in other words, the probability of two observers choosing the same answer[19 20]. For measurement instruments used in clinical practice, the percentage agreement is more suitable than other measures (e.g., κ) and easier for clinicians to interpret[21]. κ is a relative measure, a measure of reliability, whereas percentage agreement is an absolute measure. In clinical practice, the probability that another rater would give the same answers is of interest to healthcare workers. Therefore, percentage agreement was calculated between the observers for all four response categories and for the dichotomous categories. The four-point Likert scale was dichotomized by recoding the scores as follows: 'Not present at all' and 'Slight degree of presence'= 0, 'Moderate degree of presence' and 'Great degree of presence' = 1. A percentage agreement of ≥70% was considered high. Interobserver agreement was based on scores between observers one and two on day 1, and between observers three and four on day 3. To analyze the intraobserver agreement, scores were used between observer one on day 1 and 2, and between observer three on day 3 and 4. Separate analyses were conducted for the observations during rest and during movement. Analyses were performed with IBM SPSS Statistics version 25.0 for Windows.

Results

Characteristics of residents & observers

Residents were recruited between November 2014 and March 2015 from five different nursing homes. In total, 45 residents met the inclusion criteria and were included in this study. The mean age of the residents was 85.7 (SD 7.0) years, 80% was female, 57% was diagnosed with Alzheimer's disease and 71% was in an advanced stage of dementia (Reisberg GDS score 6–7) (Table 1). The average length of stay in the nursing home was 29.5 (SD 24.5) months.

Of the 28 observers, data on characteristics of four observers were missing (Table 1). All the observers were female; of these, about half were nursing assistants, 33% were registered nurses and 8% were nurses in training. As assessed on a 0–10 Likert scale (higher scores indicating higher level of confidence) nurses felt moderately confident (7.4, SD 2.0) to assess pain in persons with dementia. Furthermore, more than half of the nurses indicated that no pain measurement instrument was used in their organization for daily practice to assess pain in persons with dementia.

Table 1. Characteristics of the study population, residents and observer/raters

Residents (n = 45)	
Age	85.7 (SD: 7.0)
Gender	
Male	9 (20%)
Female	36 (80%)
Length of stay (months; n = 44)	29.5 (SD 24.5)
Dementia severity: GDS (n = 43)	
- GDS 5 (moderate-severe)	11 (26%)
- GDS 6 (severe)	14 (33%)
- GDS 7 (very severe)	18 (42%)
Type of dementia (n = 44)	
- Alzheimer's disease	25 (57%)
- Vascular dementia	3 (7%)
- Mixed dementia	3 (7%)
- Other	1 (2%)
- Not specifies or unknown	12 (27%)
Raters (n = 28)	**N = 4 missing**
Profession	
- Registered nurse	8 (33%)
- Nursing assistant	14 (50%)
- Nurse in training	2 (8%)
Confidence identifying pain in dementia[†]	7.4 (SD: 2.0)
Pain measurement instruments used in organization?	
- Yes	13 (54%)
- No	11 (46%)
How often do you use pain measurement instruments in daily practice?	
- Never	13 (54%)
- < 1 x month	10 (42%)
- 1-2 x month	-
- 1 x week	1 (4%)
- Almost daily	-

[†]Likert scale 0–10, with higher cores indicating a higher level of confidence.
GDS: Global deterioration scale; SD: Standard deviation.

Presence of behaviours described in the individual PAIC-36 items

Table 2 presents the proportion of the behaviour described in the different items that were present (in any degree) during rest and movement.

Facial expression

During rest, four items of the facial expression domain had low item prevalence: 'raising upper lip' (7%), 'clenched teeth' (9%), 'teary eyed' (4%) and 'looking frightened' (11%). During movement, only the items 'raising upper lip' and 'teary eyed' had low prevalence rates: both 9%. During rest, six items had a prevalence rate of ≥ 34%: 'frowning', 'empty gaze', 'seeming disinterested', 'pale face', 'looking tense', and 'looking sad'.

During movement, nine items had a prevalence rate of ≥ 34%, with the highest percentage of 60 and 62% for the items 'empty gaze' and 'looking tense'. Compared with the rest situation, the items 'narrowing eyes' (p = 0.03), 'looking tense' (p = 0.01) and 'looking frightened' (p = 0.001) were significantly more present during movement.

Body movements

During rest, three items had an item prevalence of 2%: 'resisting care', 'limping' and 'pacing'. The item 'pushing' was not present at all. The item 'pacing' was not present during movement. Furthermore, the items 'pushing'' (4%), 'guarding' (7%) and 'rubbing' (7%) also had low item prevalence. Only one item during movement had a prevalence ≥ 34: 'freezing' (44%). Additionally, compared with the rest situation, the items 'freezing' (p = 0.001) and 'resisting care' (p = 0.01) were significantly more prevalent during movement.

Vocalizations

During rest, almost all items had low item prevalence, especially the items 'using pain related words' (2%) and 'screaming' (2%). During movement only three items had a low prevalence: 'using offensive words' (2%), 'screaming' (9%) and 'crying'' (2%). The item 'sighing' had a high item prevalence, that is, 47%. Compared with the rest situation, the items 'using pain-related words' (p = 0.002), 'groaning' (p = 0.02) and 'sighing' (p = 0.004) were significantly more often present during movement.

Table 2. Presence of behaviours described in the PAIC-36 during rest and movement

PAIC item	Rest† (n = 45) Percentage of present (any degree)	Movement† (n = 45) Percentage of present (any degree)	*p*-value
Facial expressions			
Pained expression	20	40	0.06
Frowning	33	42	0.45
Narrowing eyes	18	44	**0.03**
Closing eyes	31	31	1.00
Raising upper lip	7	9	1.00
Opened mouth	22	40	0.10

Table 2. Presence of behaviours described in the PAIC-36 during rest and movement *(continued)*

PAIC item	Rest† (n = 45) Percentage of present (any degree)	Movement† (n = 45) Percentage of present (any degree)	*p*-value
Tightened lips	27	33	0.63
Clenched teeth	9	18	0.29
Empty gaze	49	60	0.36
Seeming disinterested	51	31	0.12
Pale face	42	53	0.38
Teary eyed	4	9	0,69
Looking tense	36	62	**0.01**
Looking sad	38	42	0.83
Looking frightened	11	44	**0.001**
Body movements			
Freezing	13	44	**0.001**
Curling up	13	18	0.79
Clenching hands	18	33	0.14
Resisting care	2	24	**0.01**
Pushing	0	4	0.50
Guarding	16	7	0.34
Rubbing	20	7	0.07
Limping	2	16	0.07
Restlessness	40	20	0.06
Pacing	2	0	1.00
Vocalizations			
Using offensive words	4	2	1.00
Using pain relates words	2	31	**0.002**
Repeating words	4	11	0.45
Complaining	11	18	0.58
Shouting	4	16	0.13
Mumbling	22	31	0.50
Screaming	2	9	0.38
Groaning	9	31	**0.02**
Crying	4	2	1.00
Gasping	7	16	0.29
Sighing	18	47	**0.004**

†Rest: for example, sitting in a chair; Movement: for example, a transfer or repositioning in bed (with/without help) as part of care as usual. Numbers printed bold: ≤0.05 significant.

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Observer agreement

Interobserver agreement

Table 3 presents the interobserver agreement of the 36 individual PAIC items during rest and movement. For each item the percentage agreement (for a dichotomous and four-category outcome) is presented.

Facial expressions
During rest, nine items had a high percentage agreement (≥ 70%) for interobserver agreement with regard to the item being present or not: 'pained expression' (84%), 'closing eyes' (78%), 'opened mouth' (73%), 'tightened lips' (73%), 'clenched teeth' (82%), 'teary eyed' (89%), 'looking tense' (73%) and 'looking frightened' (89%). The item with the highest percentage agreement was 'raising upper lip' (91%).
The percentage agreement for the four-category outcome was ≥70% for the items 'pained expression', 'clenched teeth', 'teary eyed', 'looking frightened', and with the highest percentage agreement of 91% also for the item 'raising upper lip'.
During movement, the percentage agreement with regard to the item being present or not was ≥ 70% for the items: 'raising upper lip', ''clenched teeth', 'pale face', 'teary eyed' and 'looking frightened'. The agreement for the four-category outcome was high (both 84%) only for 'raising upper lip' and 'teary eyed'.

Body movements
During rest, all items of the body movement domain had an agreement of ≥ 70% for both four category and dichotomous outcomes except for the item 'restlessness'. This item had a percentage agreement of 64% for the item being present or not and 62% agreement for the four-category outcome. The item 'pushing' had a percentage agreement of 100% for both the dichotomous category and the four-category outcome. The agreement on the items during movement was also high. Eight items of the dichotomous category outcome and seven items of the four-category outcome had an agreement of ≥ 70%, with the highest agreement of 96% for the item 'pacing'.

Vocalizations
During rest, all 11 items of the vocalization domain had a high percentage agreement (≥ 70%) for the dichotomous category outcome. This also applied to the percentage agreement of the four-category outcome, except for the item 'mumbling' (69%).
During movement, ten items had a high percentage agreement for the dichotomous category outcome, with the highest agreement of 93% for the items 'using offensive words' and 'crying'. Only the item 'mumbling' had an agreement of 67%. For the percentage agreement of the items regarding the four-category outcome, only two items had a percentage agreement ≤ 70%: 'mumbling' (58%) and 'sighing' (60%).

Table 3. Interobserver agreement of the PAIC-36 (90 observations in 45 residents)

PAIC item	Interrater reliability			
	Rest[†]		Movement[†]	
	Percentage of agreement dichotomous ('yes'/'no')	Perentage of agreement all responses (0-3)	Percentage of agreement dichotomous ('yes'/'no')	Perentage of agreement all responses (0-3)
Facial expressions				
Pained expression	84	82	69	60
Frowning	56	53	38	29
Narrowing eyes	69	69	69	51
Closing eyes	78	69	62	56
Raising upper lip	91	91	87	84
Opened mouth	73	69	60	51
Tightened lips	73	69	69	60
Clenched teeth	82	82	76	69
Empty gaze	67	51	53	40
Seeming disinterested	69	56	64	56
Pale face	67	60	73	69
Teary eyed	89	89	87	84
Looking tense	73	67	69	47
Looking sad	69	53	56	49
Looking frightened	89	87	76	56
Body movements				
Freezing	84	84	60	44
Curling up	89	84	71	69
Clenching hands	82	76	69	60
Resisting care	98	98	78	71
Pushing	100	100	89	89
Guarding	80	78	84	82
Rubbing	82	78	91	89
Limping	96	96	76	71
Restlessness	64	62	78	73
Pacing	98	98	96	96

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Table 3. Interobserver agreement of the PAIC-36 (90 observations in 45 residents) *(continued)*

PAIC item	Interrater reliability			
	Rest[†]		Movement[†]	
	Percentage of agreement dichotomous ('yes'/'no')	Perentage of agreement all responses (0-3)	Percentage of agreement dichotomous ('yes'/'no')	Perentage of agreement all responses (0-3)
Vocalizations				
Using offensive words	96	96	93	93
Using pain-related words	91	89	80	73
Repeating words	98	86	82	82
Complaining	87	84	73	71
Shouting	100	98	82	78
Mumbling	71	69	67	58
Screaming	96	96	87	84
Groaning	89	89	84	73
Crying	89	89	93	93
Gasping	89	89	84	84
Sighing	78	73	73	60

[†]Rest: for example, sitting in chair; Movement: for example, a transfer or repositioning in bed (with/without help) as part of care as usual. PAIC: Pain Assessment in Impaired Cognition.

Intraobserver agreement

Table 4 presents the intraobserver agreement of the individual PAIC items for both rest and movement. For each item, the percentage agreement (for a dichotomous and four-category outcome) is presented.

Facial expressions

During rest, only the item 'closing eyes' had a percentage agreement just below 70% for the dichotomous category outcome. The other 14 items had percentages ≥ 70%, with the highest percentage agreement for the item 'teary eyed' (98%). For the scores in the four-category outcome, fewer items had high percentage agreement: eight of 15 items scored ≥ 70%, with the highest score again for the item 'teary eyed' (95%). Compared with rest, only ten items scored ≥ 70% for the dichotomous category outcome during movement, with the highest percentage agreement of 85% for both 'raising upper lip' and 'teary eyed'. The item 'frowning' had the lowest percentage agreement of 55%. This also applied to the four-category outcome. Furthermore, only the items 'closing eyes', 'raising upper lip', 'clenched teeth', 'seeming disinterested' and 'teary eyed' had a percentage agreement of ≥ 70%. Overall, the percentage agreement of the items in the

dichotomous category outcome during both rest and movement were higher compared with the percentage agreement in the four-category outcome.

Body movements

During both rest and movement, almost all items (in both the dichotomous category outcome and the four-category outcome) had a high percentage agreement of ≥ 70%. The lowest percentage agreement was for the item 'restlessness' during rest (63% dichotomous category outcome; 53% four-category outcome) and for the item 'freezing' (65%) during movement (dichotomous category outcome). During rest, the items 'resisting care', 'pushing' and 'limping' had the highest percentage agreement of 98% (for both categories). During movement, the item 'pacing' had the highest percentage agreement (93%) for both categories.

Vocalizations

During rest, all vocalization items had a high percentage agreement for both the dichotomous category outcome and the four-category outcome. The items 'using offensive words' and 'screaming' had the highest agreement of 95%. During movement, only the item 'groaning' had a lower percentage agreement for the dichotomous category outcome (65%) and for the four-category outcome (55%). Also, the items 'using pain-related words' and 'complaining' had a lower percentage agreement: 63%. During movement, the item 'using offensive words' had the highest percentage agreement (95%), followed by the item 'screaming' (88%).

Table 4. Intraobserver agreement of the PAIC-36 (80 observations in 40 residents*)

	Interrater reliability			
	Rest[†]		**Movement**[†]	
PAIC item	**Percentage of agreement dichotomous ('yes'/'no')**	**Percentage of agreement all responses (0-3)**	**Percentage of agreement dichotomous ('yes'/'no')**	**Percentage of agreement all responses (0-3)**
Facial expressions				
Pained expression	90	78	60	50
Frowning	70	60	55	35
Narrowing eyes	70	70	63	55
Closing eyes	63	55	75	73
Raising upper lip	88	88	85	80
Opened mouth	75	70	60	50
Tightened lips	78	70	65	60
Clenched teeth	85	83	73	70
Empty gaze	70	65	73	68

Table 4. Intraobserver agreement of the PAIC-36 (80 observations in 40 residents*) *(continued)*

PAIC item	Interrater reliability			
	Rest[†]		Movement[†]	
	Percentage of agreement dichotomous ('yes'/'no')	Percentage of agreement all responses (0-3)	Percentage of agreement dichotomous ('yes'/'no')	Percentage of agreement all responses (0-3)
Facial expressions				
Seeming disinterested	78	65	73	70
Pale face	75	65	83	63
Teary eyed	98	95	85	88
Looking tense	75	68	70	53
Looking sad	83	68	70	58
Looking frightened	76	78	75	68
Body movements				
Freezing	80	80	75	65
Curling up	83	83	85	80
Clenching hands	88	85	75	70
Resisting care	98	98	83	73
Pushing	98	98	85	80
Guarding	80	80	80	75
Rubbing	83	80	90	88
Limping	98	98	73	70
Restlessness	63	53	83	75
Pacing	95	95	93	93
Vocalizations				
Using offensive words	95	95	95	95
Using pain-related words	85	85	73	63
Repeating words	90	85	83	80
Complaining	85	80	70	63
Shouting	88	88	83	78
Mumbling	80	78	85	73
Screaming	95	95	93	88
Groaning	78	78	65	55
Crying	93	93	80	80
Gasping	85	85	85	85
Sighing	80	73	85	74

[†]Rest: for example, sitting in chair; Movement: for example, a transfer or repositioning in bed (with/without help) as part of care as usual. *Five pairs of observations missing. PAIC: Pain Assessment in Impaired Cognition.

Discussion

This study investigated the observer agreement of the Dutch version of the 36 PAIC items. The results show that both the interobserver and intraobserver agreement of most individual items of the PAIC is good (percentage agreement ≥ 70%). This applied particularly to the items in the body movement and vocalization domains. In comparison to these domains, fewer items in the facial expression domain had good interobserver and intraobserver agreement during both observations in rest and movement.

Regarding the item prevalence of the behaviours described in the different items, seven of 36 items had high item prevalence (> 30%) in both rest and movement: 'frowning', 'closing eyes', 'empty gaze', 'seeming disinterested', 'pale face', 'looking tense', and 'looking sad'. Furthermore, eight of 36 items had a low prevalence rate (< 15%) in both rest and movement: 'raising upper lip', 'teary eyed', 'pushing', 'pacing', 'using offensive words', 'repeating words', 'screaming', and 'crying'.

Most items with a low prevalence rate belonged to the body movement and vocalization domains. The relatively high number of items with low prevalence in the body movement domain was expected; for example, during rest, there is minimal movement of the musculoskeletal system when sitting in a chair[22][23]. However, only four of 15 items of the facial expressions domain had a prevalence rate of <15%. This indicates that pain might also be present during rest, related to other causes besides movement and/or the musculoskeletal system. There may be various causes for this pain. Approximately 5% of nursing home patients with dementia have orofacial pain[24], and pain might also originate from neuropathological changes in the brain, for example, white matter lesions and atrophy, which may cause central pain, also in rest2 [25-27]. This could imply that some persons with dementia are more or less in pain all the time, even in rest. Nevertheless, it is remarkable that the items 'limping' and 'pacing' were present during rest (prevalence of 2%); this might indicate that the observers did not understand the item or that they did not score during actual/real rest.

Regarding observations during movement, the overall prevalence of the individual items was higher compared with observations during rest. This was expected since, during movement, either the resident or the nurse induced physical movement (either active or passive) as part of usual care. For example, mobilizing hips or legs often generates pain originating from the musculoskeletal system. This is a known and frequent cause of pain in elderly persons due to age-related diseases such as osteoporosis and arthritis[22][23]. Although not the topic of this paper, the difference in prevalence of items observed in rest and during movement supports construct validity of the PAIC[28].

Additionally, the latter underlines that it is important that patients with dementia should be observed during different situations/activities, in other words, rest and movement, in order to detect pain accurately. This is supported by the study of Strand et al. which shows strong evidence that specific body movements, such as 'restlessness' and 'guarding', indicate pain[29]. These movements may either be more prevalent or visible during movement or during rest.

It might be assumed that items with low prevalence rates are not informative enough for pain and, therefore, are not suitable for the measurement of pain in persons with dementia. On the other hand, items with low prevalence rates might still be informative,

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but only for high pain intensities and may therefore help to encode pain intensities. Additionally, lower inter- and intraobserver agreement might also mean that interpretation of these items is difficult and/or the meaning of the item is not easily understood, making it difficult to score. For example, a study that examined the content validity of the PAIC reported that almost half of the items of the vocalization domain were not interpreted as an expression of pain, but as a symptom of dementia[12].

The present study revealed lower inter- and intraobserver agreement for the facial items compared with the body movement and vocalization domains. This might suggest that facial expressions are more difficult to observe/evaluate in a clinical setting. It has been reported that recognizing and observing facial expressions requires specific training and education[30]. Also, more variation in grading (use of the 4-category outcome) can lead to a lower percentage agreement. This could also apply to the other domains of the PAIC. Furthermore, a possible explanation for the low intraobserver agreement and even lower interobserver agreement is that nurses may not be accustomed to focus on/recognize facial expressions, especially during movement of the resident[31]. At last, facial items can be of (very) short duration and, thus, easily missed.

Regarding the use of different scoring options (dichotomous category outcome versus four-category outcome), more items had a high percentage agreement using the dichotomous category outcome compared with using the four- category outcome. However, using the four-category outcome seems more sensitive to detect (small) changes over time and to monitor treatment effect. On the other hand, filling out only 'yes' or 'no' may be easier for the observer and less time consuming. Moreover, for solely identifying pain, this is sufficient.

Strength & limitations

This was a multicenter observational study performed in five nursing homes. The inter-observer and intraobserver agreement was tested using percentage agreement, as this represents the actual agreement without adjusting for chance agreement (as does, e.g., κ)[20][21]. In clinical practice, since chance agreement cannot be disentangled from actual agreement, adjusting for this is clinically irrelevant. This is why we chose not to report κ statistics. Furthermore, reporting the percentage agreement makes it easier for clinicians to interpret the agreement of the PAIC and decide whether the PAIC is suitable for clinical practice. Additionally, observer agreement was tested in a relatively large population (n = 45) and with a large number of observations[19]. Furthermore, the observations took place in a real-life setting during situations of rest and movement, which represent usual care situations. Moreover, using multiple observers reflects a real-life setting. Additionally, the population is thought to be representative of nursing home residents with high scores on the GDS 7 (42%), indicating very severe dementia[18]. In the more severe stages of dementia, communicative abilities are generally diminished and sometimes even completely absent[32]. In these patients, an observational measurement instrument to identify pain, such as the PAIC, is indispensable.

A possible limitation of the study is that there was variation in the knowledge and/or experience of the observers. Whereas the observers felt relatively confident in identifying pain in persons with dementia (7.4, SD: 2.0), ≤ 50% had never used an observational

measurement instrument to measure pain (Table 1); this might suggest that some observers had difficulty filling out the PAIC. However, all observers received a short training at the beginning of the observations, as PAIC is intended to be used reliably and without specific extensive training. However, variation in the knowledge and experience of the observers might also be considered a strength of this study, as this represents the real-life clinical setting of a nursing home. Nevertheless, more extensive training in using observational pain measurement instruments might lead to higher reliability scores.

Furthermore, there is ongoing discussion regarding which parameter can best be used to examine the reliability of the PAIC. Percentage agreement does not adjust for possible chance agreement. Therefore, percentage agreement represents the realistic amount of observer agreement that actually exists[21]. For the PAIC, examining the percentage agreement is preferred because, besides identifying pain, the PAIC is also applied to measure changes over time, thereby monitoring treatment.

Conclusion

This study shows that the 36 items of the Dutch version of the PAIC-36 have generally good inter- and intraobserver agreement, especially for the body movement and vocalization domains. Although all items were extracted from existing and established scales, it is surprising that some items of the PAIC-36 had low percentage agreement in a clinical setting. A next step in the development and refinement of the PAIC is possible item reduction to increase the probability of successful implementation of the PAIC in daily clinical practice. The decision whether or not to include a specific item needs to be made in combination with other (psychometric) studies from more countries/cultures. Also, the reliability of the facial expression items (and the PAIC items in general) might be further improved by (interdisciplinary) education on pain in persons with dementia and the training of nursing home staff on how to use a pain measurement instrument. Education and training might increase the clinical utility and feasibility of the PAIC.

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Financial & competing interests disclosure

Ethical conduct of research

The authors state that they have obtained appropriate institutional review board approval and have followed the principles outlined in the Declaration of Helsinki for all human investigations. The Medical Ethics Committee of the Leiden University Medical Centre approved this study and gave a waiver of consent. Due to the cognitive impairment of the included residents, written informed consent was obtained from the patient's legal representative. When possible, written informed consent was also obtained from the residents themselves.

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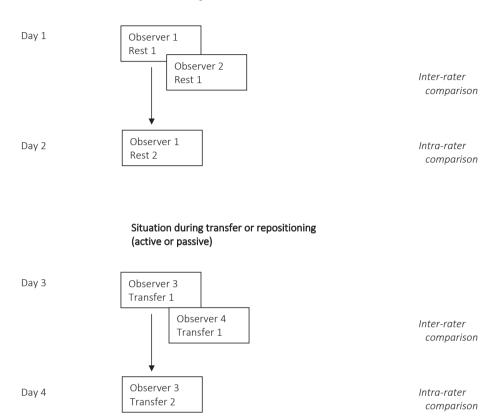
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Appendix 1. Scheme of observations for each resident

Situation during rest

Day 1

```
Observer 1
Rest 1
        Observer 2
        Rest 1
```

Inter-rater comparison

Day 2

```
Observer 1
Rest 2
```

Intra-rater comparison

Situation during transfer or repositioning (active or passive)

Day 3

```
Observer 3
Transfer 1
        Observer 4
        Transfer 1
```

Inter-rater comparison

Day 4

```
Observer 3
Transfer 2
```

Intra-rater comparison

6

Day x

```
Additional 10 video recordings,
5 during rest and 5 during transfer or
repositioning (in 5 or 10 participants)
to be rated by 12 to 50 observers
```